Legislative Snapshot:
Number 2

Hospice

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A LEGISLATIVE SNAPSHOT

STATE LAWS RELATED TO HOSPICE CARE PROGRAMS

by Judith A. Regner

The preponderance of degenerative diseases as the leading cause of death, ever-increasing costs of long term care, a reaction to depersonalized institutional care, and more have contributed to widespread interest in "hospice care." The word hospice itself is the medieval name for a "way station for crusaders where they could be replenished, refreshed and cared for." Today, it is used to describe "an organized program of care for people going through life's last station (dying)."

Modern hospice programs trace their beginnings to St. Christopher's Hospice in England, which was initiated in 1967. Hospice, Inc., the first American hospice, was organized in New Haven, Connecticut in 1971. Interest has been so widespread, however, that over 59 separate operating programs were identified by the Government Accounting Office in March of 1979, while 73 others were reported to be in the planning stages.

Although most hospice programs are associated with facilities -- a place where people can die with dignity -- hospice programs in fact care for persons in their own homes and in existing hospitals and nursing homes. The distinguishing factor in hospice programs is their emphasis on symptom control (relief from pain) and spiritual and emotional support for both the patient and the family, rather than high-technology medical services. Most hospices emphasize a humanistic team approach, attempting to permit death to be as dignified, as painless and as peaceful as possible.

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Widespread public interest in hospice programs has resulted in considerable state governmental activity on the subject. There have been concerns about licensing and the quality of care in hospice programs, about the need for governmental assistance to start new programs, and about possible increases (or decreases) in total health care costs due to changed demand. According to the GAO, slightly more than half of the hospices operating in March 1979 held state licenses. Aside from CONNECTICUT, which adopted separate hospice licensing regulations on January 18, 1979, each of the licensed hospice programs was licensed as some other type of health provider -- generally either a hospital or home health agency or both. Two psychiatric hospitals and five skilled nursing facilities, however, also operated hospice programs at the time of the study.

In addition to issues relating to licensure, there has been concern about standards for inclusion of hospices in certificate of need programs. Under federal regulations and most state laws, hospice programs require a certificate of need before operation. The newness of the programs and resultant lack of information on need, demand or effect on total costs, however, means there are almost no criteria on which to base such decisions. Despite these problems, hospice programs around the country are submitting applications for certificate of need to various state and local health planning agencies. At least one such application has been granted in FLORIDA, while others have been turned down in ALABAMA and NEW JERSEY.

As of late 1979, at least eight states had enacted legislation relating to hospice care. Five of these states -- CALIFORNIA, MARYLAND, NEW YORK, OREGON and VIRGINIA -- authorized study commissions and demonstration projects as a preliminary step prior to enacting regulatory legislation. CONNECTICUT and FLORIDA both established specific licensing requirements for hospice programs, although only FLORIDA, NEW YORK, and NEVADA specifically include hospice programs under their certificate of need statutes. In a non-legislative development, the state of KENTUCKY is now in the process of developing guidelines for reviewing certificate of need applications from hospice programs.

Most of the state laws contain similar definitions of "hospices," (only MARYLAND fails to define the term). CALIFORNIA, CONNECTICUT, FLORIDA, NEVADA, NEW YORK, OREGON and VIRGINIA state that hospices are programs extending services to terminally ill persons and their families to meet physical, psychological, social and spiritual needs. Each of these states, except NEVADA, also specify the use of a team approach, the provision of home and inpatient care, and extension of services to the family through the bereavement period. CALIFORNIA, CONNECTICUT, FLORIDA, NEVADA and OREGON require that hospice programs be under the direction of a physician, but NEW YORK and VIRGINIA's statutes are silent in this regard. CONNECTICUT, FLORIDA AND OREGON

all mention the use of volunteers in their definitions of hospice care.

The five states establishing study commissions on hospice care have taken different approaches. The VIRGINIA study commission will look at existing hospice programs. In CALIFORNIA, the legislature is requiring the Department of Health Services to conduct at least two hospice pilot projects. In fact, the state has contracted with four hospice programs, each representing different models of care. The Department is mandated to investigate possible MediCal (Medicaid) reimbursement for hospice care, to evaluate quality and cost effectiveness of hospice care, and to assess the current and projected need for such care. Projects are funded for one year through an appropriation of $160,000, and recommendations are to be made to the legislature not later than April 1, 1980.

NEW YORK's demonstration project extends over three years, establishing three models of hospice care that will be licensed if each proves effective. Each model of hospice care is required to provide home care, with backup inpatient beds provided by either

A. A free-standing hospice facility;

B. A special autonomous unit of a general hospital or nursing home; or

C. Whatever unit of a general hospital to which a patient is originially admitted.

The MARYLAND legislature has established a 13 member study commission to determine what types of hospice care are currently available in the state, what unmet needs for hospice care exist, and how the insurance industry and the Maryland Medical Assistance Program (Medicaid) can be organized to meet those needs. OREGON established a task force to analyze the need for regulations and guidelines related to staffing, record keeping, quality of care and administration of hospice programs.

Only two states, CONNECTICUT and FLORIDA, have established specific statutory requirements for licensing hospices. CONNECTICUT, the site of the nation's first formal hospice program, has extremely detailed statutory and regulatory requirements. Recently promulgated regulations specify physical characteristics of a licensed facility, enumerate duties of the governing board, and list job specifications for hospice care staff. FLORIDA's recently enacted legislation lists various requirements for a hospice program, as well as detailing procedures for obtaining a license. Both states

protect the confidentiality of patient records and require written consent for the release of information.

FLORIDA, NEVADA and NEW YORK specifically include hospice programs under their certificate of need program. None of these states establishes specific guidelines in statute for granting or denying a certificate of need to a hospice. KENTUCKY is currently drafting such guidelines for hospice programs under their generic certificate of need law, but no legislative changes relating to hospices have been made to that statute. In 1978, CONNECTICUT passed a law requiring health insurance policies to cover home health care services for terminally ill persons whether or not the person was hospitalized prior to receiving the service.

There has been a considerable amount of legislative activity related to hospice programs that did not result in new laws. As further experience with hospices is accumulated nationwide, however, additional legislative activity is certain to ensue. For instance, two hospice care bills were introduced in HAWAII in 1979. SB 135 would have established a hospice care program, while SB 136 would have required insurance coverage for hospices. In ILLINOIS, the legislature approved a bill to establish a study commission to investigate the possibility of adopting a statewide hospice program. It was vetoed by the Governor, however, and never became law. A bill in MARYLAND (HB 133) would have provided Medicaid funds for hospice care, but was defeated.

A bill in IOWA proposed to require health insurance coverage for home and inpatient hospice care (HB 618), while a MICHIGAN bill would have allowed the Public Health Department to license hospice programs. Two similar proposals in NEW JERSEY (SB 43 and SB 358) would have amended the state's existing Juvenile Terminal Illness Assistance Act by extending its coverage to all terminally ill persons. A 1979 WEST VIRGINIA proposal (HB 1400) would have required the establishment of a hospice program under the Department of Health and would have set standards for a facility to qualify for financial aid. None of these bills were enacted.

The Intergovernmental Health Policy Project has full text copies of each of the enacted state laws relating to hospice care. They are available upon request. (Please enclose a self-addressed label -- it is extremely helpful to our staff.)

For further information on hospice care programs, we have listed the phone numbers of the individuals in various states and

nationally who have been helpful in providing hospice information. In addition, the General Accounting Office conducted an excellent review of existing programs, characteristics of patients, and sources of actual and possible funding for hospice programs. It is entitled Hospice Care -- A Growing Concept in the United States (HRD 79-50; March 6, 1979). Single copies are available free of charge by calling (202) 275-6241.

The Health Resources Administration has compiled a useful listing of publications discussing hospice programs. It is #15 in the Health Planning Bibliography Series, and is entitled HOSPICES AND RELATED FACILITIES FOR THE TERMINALLY ILL: SELECTED BIBLIOGRAPHIC REFERENCES. This document is available from the Government Printing Office (HRP - 0301501) or by writing to the

Health Planning Information Center
P.O. Box 1600
Prince George's Plaza Branch
Hyattsville, Maryland 20788

The National Hospice Organization has published two reports of interest to state legislatures and health departments studying possible licensure and/or reimbursement issues of hospice care programs. They are: Delivery and Payment of Hospice Services: An Investigative Study (September 1979 -- $20 to non members); and Standards of a Hospice Program of Care ($12 to non members). Contact the National Hospice Organization, Tower Suite 506, 301 Maple Avenue West, Vienna, Virginia 22180.

Note: Every attempt was made to be as comprehensive as possible in listing current state laws relating to hospice care programs, however, some omissions may occur. The Intergovernmental Health Policy Project would appreciate being kept updated about any further developments.

CONTACT PEOPLE

California - Peggy Falknor
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(415) 540-2350

Connecticut - Dennis Rezendes or
John Abbott
Connecticut Hospice
(203) 787- 5871

Florida - Sue Hester
Aging Program Specialist
Department of Health and Rehabilitation Services
(904) 488-6621

Kentucky - Alice Towber (person working on drafting regulations)
(502) 564-7520

Maryland - Mike Volk (temporary contact until committee is formed)
Legislative Policy Committee
(301) 269-2367

Michigan - Mike Spiece (Rep. David Hollister's office)
(517) 373-0826

Nevada - Shirley Pate
Bureau of Health Facilities
(702) 885-4475

New York - Bob Dougherty
Asst. Dir. of HMO's and home health services
(518) 474-7354

Oregon - Gary Jacobsen, M.D.
Chairman of Study Commission
(503) 225-8706

Alan Tresidder
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(503) 378-8871

Virginia - Lelia Hopper
Legislative Services
(804) 786-3591

Washington, D.C. - Claire Shanks
National Hospice Organization
(703) 938-4449

Washington, D.C. - Health Care Financing Administration

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CALIFORNIA - Assembly Bill 1586 - 1978

This bill requires the State Department of Health Services to conduct at least two hospice pilot projects, to establish regulations, and to recommend levels of reimbursement, for MediCal recipients. For a one-year period, funding for the pilot projects is available through a grant to non-profit hospice organizations and MediCal reimbursement available to eligible patients and their families. At least one grant is required to be made to an organization providing in-home hospice care.

The Department of Health Services must report to the legislature by April 1, 1980. The report must include:

- An evaluation of the possibility of MediCal reimbursement for hospice care and if appropriate, recommendations on rates and regulations.

- An assessment of the quality and cost-effectiveness of:
  A. The use of lay volunteers;
  B. Hospice versus traditional care; and,
  C. Institutional versus in-home hospice care.

- An assessment of the current and projected demand for hospice care, and an assessment of the need for new facilities versus the use of existing facilities.

The legislature appropriated $160,000 to carry out the act, and stipulated that any available federal funds should be sought and utilized.

CONNECTICUT - Public Act 78-76 - (Substitute Senate Bill 289) 1978

This act amends existing law to require individual and group health insurance policies to cover home health care services for terminally ill persons even if the patient has not been hospitalized or a seven day discharge planning requirement has not been met. This applies to persons who have been diagnosed by a physician as terminally ill with a prognosis of six months or less to live.

This act enumerates the various services categorized as home health care, adding medical social services for the terminally ill, and stating that the yearly benefit for these services shall not exceed $200.

CONNECTICUT - Regulations of the State Department of Health
Section 19-13-D4b, effective January 18, 1979

These regulations were developed by the State Department of Health for the purpose of establishing a new classification for hospices. These regulations apply only to free-standing facilities and distinct hospice units. Such facilities must obtain a license and must conform to the detailed specifications relating to physical construction, administrative structure and staffing requirements as set forth in these lengthly regulations (219 pp.). A provision for accessibility to the handicapped is also included.

The regulations regarding the physical structure give detailed specifications for the size and design of patients' rooms, nursing stations and service areas. Space is to be provided for religious purposes as well as a separate room for the viewing of a deceased patient's body.

Mechanical systems such as water, air conditioning, heating and ventilation, plumbing, gas and vacuum systems, and electrical systems must meet rigid standards.

The code is equally detailed in regard to administrative structure and staffing qualifications, patient-staff ratios and duties. Administrative authority for the facility and the program is vested in a governing board. Sections on staffing and services include: medical, nursing, pharmaceutical, social work, pastoral care, the arts, volunteers, diagnostic and palliative services, respitory care, rehabilitation, and dietary services.

Record keeping requires a complete history and physical examination and a problem oriented record to be completed within 24 hours of admission. Records are to be kept confidential with written consent needed for any release of medical information.

The components of home care and out patient services are also presented. The home care program must provide medical staff availability on a 24 hour basis.

These regulations cover all aspects of a hospice facility and program in a very comprehensive manner.

FLORIDA - Senate Bill 1255 - 1978

This bill provides for the creation of hospice programs to be administered by the Department of Health and Rehabilitative Services. Hospices are identified as autonomous, centrally located non profit programs which provide a continuum of care for terminally ill persons and their families. It establishes: staffing requirements for the care team; an administrative structure; record keeping requirements; and program components. Records must be kept confidential, with written consent needed for any disclosure of patient information. Hospice programs are required to provide home care, home-like inpatient care, and outpatient care. General requirements include:

- Coordination with other community services;
- Provision of symptom control;
- Medical direction;
- 24 hour availability of service;
- A bereavement program;
- Emphasis on fostering independence; and
- A continuum and continuity of care.

After July 1, 1980, a license will be required for the provision of hospice service by a free-standing or distinct hospice unit, or for the provision of outpatient services offered under the authority of a hospice program. Procedures for licensure are included. Licenses are issued for one year and a certificate of need is required to obtain a license. Any current provider of health care who expands service to include hospice care must apply for a new certificate of need. Aspects to be considered in the certificate of need determination are enumerated, focusing on the need in relation to health plans, existing facilities, and financial feasibility.

The intent of this legislation is to support the establishment and evaluation of health goals to meet community needs, and to ensure coordination by the state health planning agency to provide necessary services and avoid duplication.

MARYLAND - House Joint Resolution 38 - 1979

This resolution established a thirteen member Hospice Reimbursement Study Commission to determine what types of hospice care are now available in the state, what types of necessary services are not presently available, what types of services would be beneficial to terminally ill persons and their families, and how the insurance industry and the Maryland Medical Assistance Program can be organized to provide the needed forms of coverage. These funding sources do not currently recognize hospices as a separate category of provider.

The Maryland Health Planning and Development agency will provide staff assistance and budget for the study commission. A report on the commission's findings is due by November, 1980.

NEVADA - Senate Bill 466 - 1979

This act defines hospice and includes it in the category of health and care facilities. By inclusion in Nevada's generic definition of health and care facilities, hospices are automatically included in the state's certificate of need and facility licensing laws.

NEW YORK - Chapter 718 - 1978

This act authorizes the Public Health Council to establish a hospice demonstration program to evaluate the use of hospices within the health care system of the state and to aid in the establishment of regulations governing subsequent certification and operation of hospices, including a reimbursement methodology showing cost benefit.

Hospice is added to the existing definition of "hospital," thus requiring hospice programs to obtain a certificate of need. For the purpose of the demonstration programs, however, the certificate of need requirements are waived. Other provisions of the public health law may also be waived for the model programs at the discretion of the commissioner of health.

The demonstration program is designed to evaluate three hospice models, each providing home care but with back up inpatient care provided:

- In an autonomous unit of a hospital or nursing home;
- In a free-standing facility; or
- In whatever unit of a general hospital to which the patient may be admitted.

A report of findings and recommendations for legislation relating to the development and use of hospices is due by March 1, 1983.

On November 29, 1979, the State Hospital Review and Planning Council adopted a new Part 86-6 of the New York State Hospital Code. It establishes reimbursement rules for the hospice demonstration program -- essentially a budget review approach with retroactive adjustments.

OREGON - House Bill 2807 - 1979

This bill authorizes the appointment of a task force to study the need for regulation of hospice programs, to indicate the level of legislation required, and to develop criteria and/or guidelines appropriate to the level of regulation. The criteria and/or guidelines must be in conformance with standards and criteria developed by nationally recognized hospice organizations. They must include:

- Qualifications of staff;
- Standards for organization and quality of care;
- Record keeping procedures; and
- Provisions for contractual arrangements for professional and ancillary services.

The task force is also requested to:

- Assess the need for a continuing advisory committee on hospice care;
- Conduct hearings to gather information; and
- File a report by August 1, 1980.

To implement the act, $19,624 was appropriated.

VIRGINIA - House Joint Resolution 252 - 1979

This resolution requests the Department of Health to conduct an evaluative study of hospice programs in Virginia and to make recommendations regarding standards for the quality of care, criteria for licensing, and reimbursement of both the home care and inpatient components of hospice programs. The study is to be coordinated with the evaluation being administered by the United States Department of Health, Education and Welfare.

The Department of Health is requested to apply for the waiver of necessary Medicaid requirements to assist hospice programs in providing services to Medicaid eligible patients.

A final report must be made to the 1981 session of the General Assembly.

This legislation is the result of a joint subcommittee's conclusion that further study is needed prior to setting standards and developing licensing regulations for hospices.

Intergovernmental Health Policy Project

The Intergovernmental Health Policy Project serves a unique function in the development of the nation's health policy. It is the only university-based program in the country concentrating its research efforts exclusively on the health laws and programs of the 50 state governments. The Project provides assistance to state executive officials, legislators, legislative staff and others who need to know about important developments in other states. At the same time, the IHPP helps federal officials identify innovative state health programs and specific state problems.

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